

NYC Coalition to End Racism in Clinical Algorithms Meeting 9



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Agenda

01 Welcome

02 Transplant Navigation Program

03 Debrief NKF Collaboration

04 Five-minute Break

05 Breakout Groups by Algorithm

06 Closing + Next Steps

Transplantation Navigation Pilot

Leo Eisenstein
&
Karina Albistegui Adler

The Problem

Undocumented people can donate organs, but they can't receive them

Nationally, they account for about 3% of all deceased organ donors, but less than 0.5% of the recipients

Who are *they*?

NATIONAL

- 10.5 million + undocumented immigrants live in the United States
- 22 million people in the U.S. live in mixed-status households
- 7.6 million in the labor force
 - Between 2000 and 2011, undocumented immigrants [generated](#) a \$35.1 billion surplus in the Medicare Trust Fund

NEW YORK

- 72500 Undocumented immigrants live in the state (fourth highest population in the US)
- 476,000 immigrants living in NYC are undocumented, 46% are uninsured
- Essential workers
 - Health care sector
 - Food Service
 - Agriculture
 - Childcare/Elder care
 - Construction

Case Study

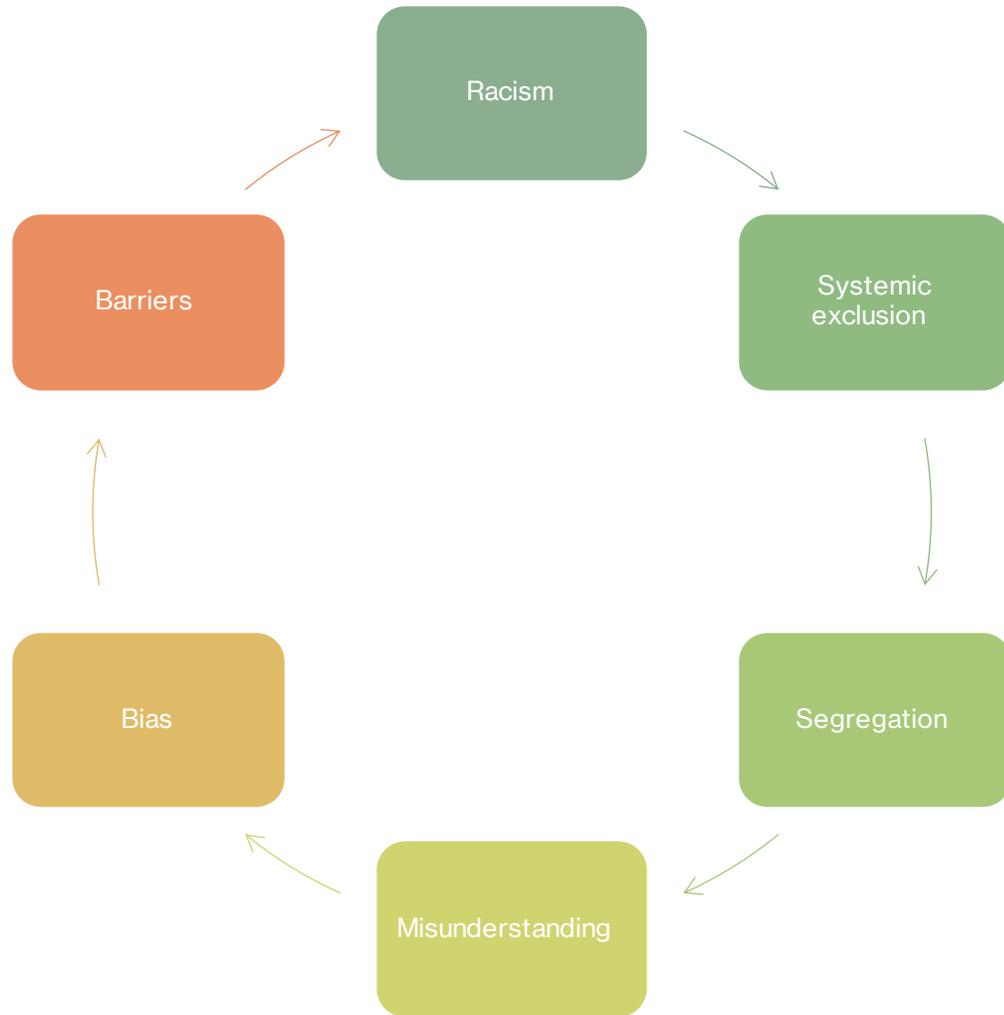
Ms G, a Spanish speaking client, called NYLPI seeking assistance in obtaining health insurance in and was able to enroll in New York's Essential Plan after qualifying for the PRUCOL eligibility category.

She secured an appointment for a kidney transplant evaluation at a large New York City transplant center. Her insurance was verified and she was scheduled. She then received a follow-up letter written in English that stated that her appointment would be canceled if she did not provide a social security number. During a follow-up call, prior to her appointment, she voluntarily disclosed that she did not have a Social Security number and her appointment was canceled on the spot.

Devastated and tearful, she called NYLPI again to request assistance. I called the transplant center and after several days and many calls and emails, I was able to have her rescheduled for a few weeks later. In the process I heard the following:

- *"It's the law"* as to why a social security number is required for scheduling
- *"She can't be listed without a social security number"*
- *" Her insurance is not the problem"*
- *"She needs proof of her [immigration] status"*
- *"We need to confirm that she has permanent insurance"*
- *"We have ways of requesting free medications" as to what would be done if a USC citizen patient suddenly lost their insurance coverage.*

Why Does This Happen?



- 1882 Chinese Exclusion Act
 - First law significantly restricting immigration in the United States
- 1996 Illegal Immigration Reform and Immigrant Responsibility Act of (IIRAIRA)
- 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) "*Welfare Reform*"
 - Denies and limits participation in Medicaid benefits to any immigrant who entered after 1996.

How NYLPI is Tackling This Problem

P.R.U.C.O.L.



Pipelines



Education



Systemic
Advocacy





P.R.U.C.O.L. Eligibility for Health Insurance

- Not an immigration status
 - ~~PRUCOL~~ letters
- New York ONLY, health insurance eligibility category
- Opens access to state funded Medicaid and the Essential Plan (ACA)
 - Means tested public benefits
- Elements
 - A federal immigration agency knows about the individual's presence;
 - permits or acquiesces to the individual's presence AND
 - The agency does not contemplate deportation
- Must meet other residency and income requirements



P.R.U.C.O.L. Eligibility for Health Insurance Some Examples

Filed an immigration application and it is *pending*;

An immigration application was *granted*;

Applicant for, Deferred Action for Childhood Arrivals;

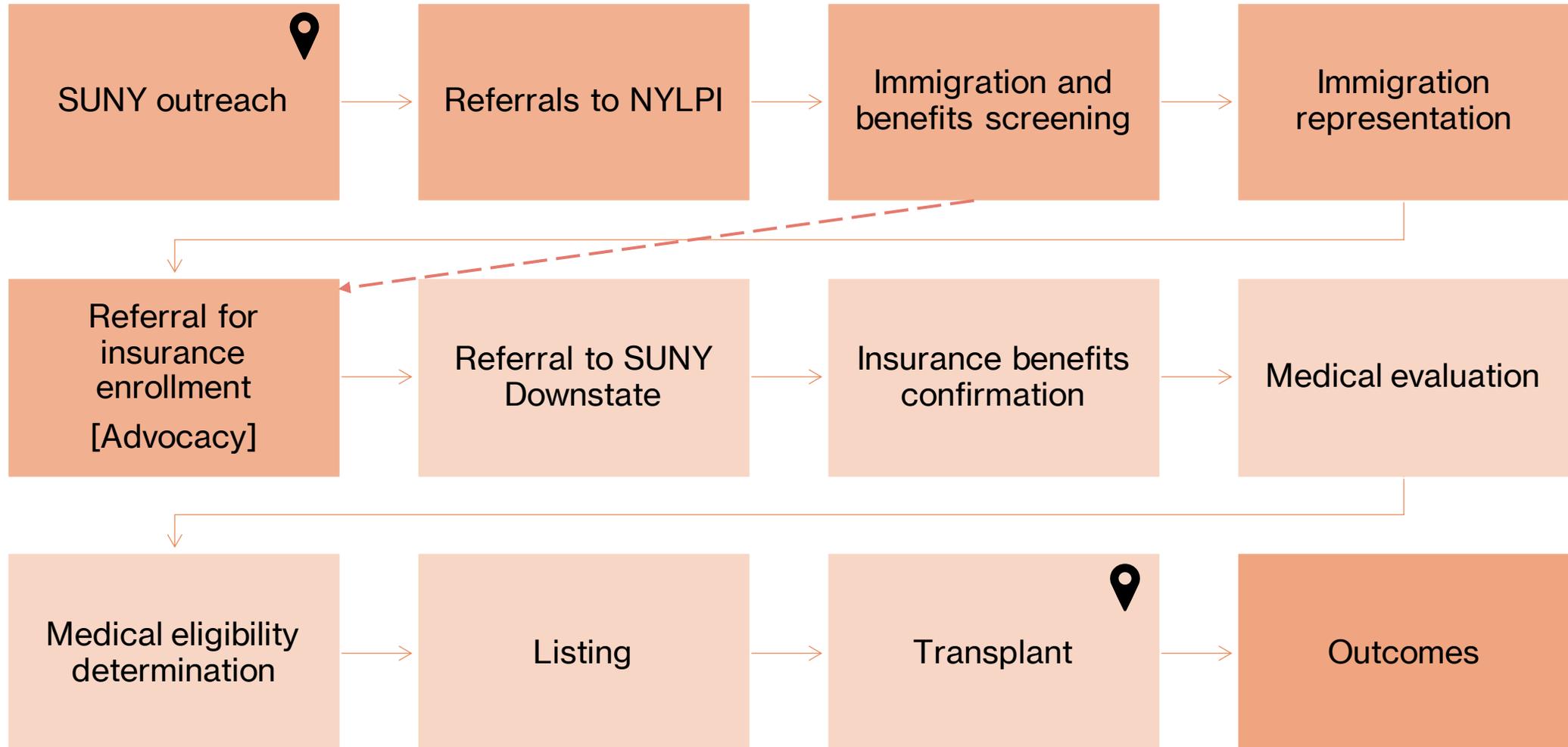
Applicant for Deferred Action based on individual circumstance;

Released from detention with an Order of Supervision (OSUP) or Humanitarian Parole;
or

Argument that (1) the federal government knows that you are here, (2) they are not contemplating deportation at this time → Ex. denied applications + no other action.



SUNY DOWNSTATE -NYLPI Pipeline





Education

ADMINISTRATIVE BARRIERS

- Lack of knowledge of public benefits
 - PRUCOL and other categories
- Requiring a social security number before scheduling (or anytime thereafter)
- Asking about immigration status before scheduling
- Not having medical interpreters available during scheduling or appointments
- Websites and materials are only in English
- Website and materials above reading level

BIAS

- Focus on immigration status / fear of imminent deportation
 - The National Organ Transplantation Act of 1984
- Questions about caregiver's immigration status
- Secondary insurance eligibility checks only for certain patients
 - Proof of certain immigration status
 - "PRUCOL letters"
- Commentary/discussion that is not evidence based.
 - Myth of poor outcomes



Systemic Advocacy

Coverage 4 All

Medicaid Expansion (1332 Waiver)

Expansion of Emergency Medicaid

Lobbying for funding for public hospitals and other public services

Strategic partnerships with hospitals, city agencies, state agencies, and elected officials

QUESTIONS?

Breakout Activity

Imagine a world where everyone where immigration status and health insurance don't play a role in access to quality healthcare. What would coordination of care between the public health system and your institution look like?

- What kind of staff do you need?
- What kind of systems do you need?
- Are there existing models for this at your current institution or elsewhere?
- What other resources do you need?
- What happens when you need to send a current patient outside of your institution for specialized testing (or just a radiology scan and bloodwork) or a second opinion?

NYLPI

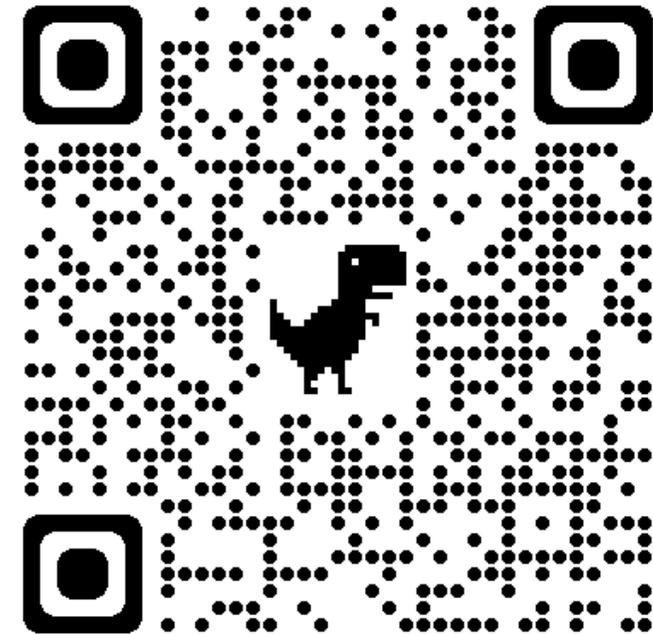


Karina Albistegui Adler
Senior Advocate

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New York Lawyers for the Public Interest is a civil rights non-profit organization that serves low-income communities of color to address environmental, disability, and health justice issues.

Health Justice Program: racial & immigrant rights focus on health care access: UndocuCare and UndocuCare TGNCI+ *Advocate for healthcare coverage for all New Yorkers, regardless of immigration status, race, or gender identity or expression.*



NKF Collaboration

Toni Eyssallenne
&
Saskia Thompson

BLACK KIDNEY HEALTH MATTERS – A GREATER NY INITIATIVE

Update as of 3.23.23

Overview

In September of 2022, National Kidney Foundation serving Greater NY (NKF-GNY) began working with the Dr. Antonia (Toni) Eyssallenne and her team at the NYC Department of Health Department of Mental Hygiene as part of the Coalition to End Racism in Clinical Algorithms (CERCA) initiative. Through thoughtful and frequent collaborations, we developed a strategy/campaign called **Black Kidney Health Matters**, which aims to:

- Raise awareness about how and why Black New Yorkers are disproportionately and unfairly impacted by kidney disease
- Acknowledge that harm has been done to the Black community as a result of prior GFR calculation in the context of other structural and social determinants of health.
- Empower Black individuals to understand their risks for CKD while calling upon health systems to recognize their role in disparities
- Provide Black individuals with tools and resources to take action (e.g. make an appointment; ask questions;)

The target audience for this campaign includes:

- Black people who live in NYC (5 boroughs); are over 30 and have one or more of the following: diabetes; hypertension; are overweight; have a family history of kidney disease.
- Live in zip codes that represent Black communities (Brownsville, East New York, Harlem, Bronx and others)
- Black people with a diagnosis of early stage of CKD (and especially those who may further along in their disease state because of a new race-free equation)
- Health care providers (towards helping them understand patient perspectives and giving them tools to discuss and acknowledge harm that has been done to Black patients with regard to CKD diagnoses).

This ongoing effort will feature:

- A series of patient-facing education programs
- Patient-facing social media to engage and inform the primary target audience
- Community engagement
- Professional education programs
- Possible press placement with the support of the NYC DOH press office

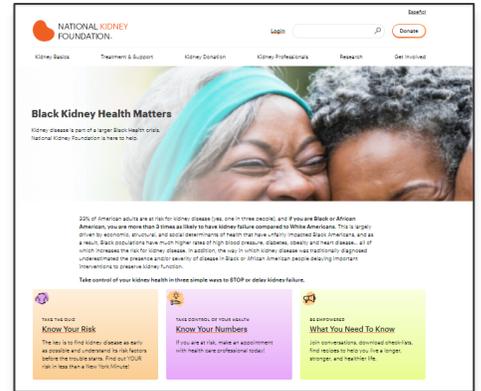
Campaign Elements & Highlights

January 2023

National Kidney Foundation serving Greater New York established a curated landing page on its website to address **Black Kidney Health in New York**. www.kidney.org/content/black-health-ny

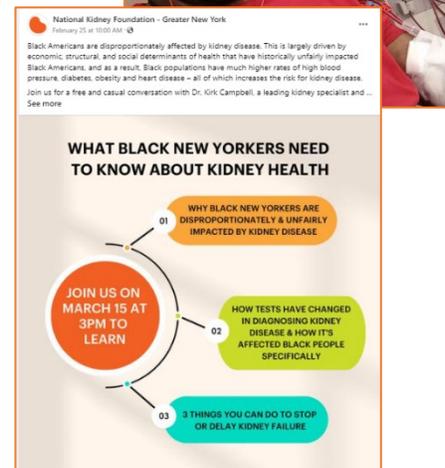
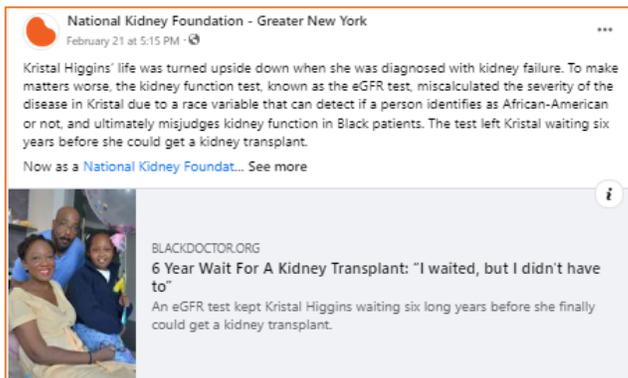
This page features: Risk Quiz; Guidance on Test Results; Links to upcoming programs; a host of resources for patients.

To further support this initiative, [NKF- GNY created an English and Spanish paper version of our Risk Quiz](#) for those who may not have access to internet, as well as a [Know Your Numbers Checklist](#) that patients can take to their appointments to better understand their test.



February 2023

During Black History Month, NKF deployed a targeted social media campaign addresses different aspects of Black health, with resources that address new GFR equation as well as risk factor and real-life experiences. The social media campaign spanned February through March 15th and largely promoted the first patient session on March 15th. **NKF boosted these posts to our targeted audiences. This campaign garnered 20,000 impressions.**



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March 2023 – Kidney Awareness Month

On March 15th, we hosted our first patient-facing program as part of this initiative entitled *What Black New Yorkers Need to Know About Kidney Health*. During this one-hour virtual session, Dr. Antonia Eyssallenne moderated a conversation among a patient, Thelma Barber, Dr. Kirk Campbell, and Dr. Dinushika Mohottige. The program was also available by dial in from a regular phone and on Facebook Live.

The program description and recording can be found here:

<https://www.kidney.org/events/local-event/what-black-new-yorkers-need-to-know-about-kidney-health>



- 110 people registered for the event with about 47 people joining live.
- All registrants were sent an ICYMI (in case you missed it) link to watch the program on demand.
- We also livestreamed the program on Facebook, which garnered an additional 31 views.
- 109 views on YouTube as of 3/23

NKF will continue to share this recording and keep it on our channel as the Black Kidney Health Matter campaign grows.

Pop Up info booths:

NKF has coordinated with DOH to identify health and community centers in heavily impacted communities to host information tables – what we are calling “Pop Ups” in the community.

BROOKLYN: Brownsville Health Action Center

March 8th | 12 pm – 3 pm.

50-60 people engaged with us/stopped at the table for resources and 26 shared contact information.

BROOKLYN InterFaith

March 22 – Virtual 11 am - 1 pm

Your Kidneys & You presentation

STATEN ISLAND: Central Family Life Center

March 24 | 12-4 pm

75-100 people expected

BROOKLYN: Brownsville Health Action Center

March 28th | 3:30 – 4:30

Your Kidneys & You Presentation – LIVE!

April – Dates TBD

Pop-ups are being planned in **East Harlem** and the **Bronx**. NKF will also collaborating with Dr. Rosa Zhou, the Director of the **Office of Faith-Based Initiatives**, who is planning a healthy living initiative involved with 50 faith-based organizations in NYC.

May 18 (to be confirmed)

NKF GNY will partner with **SUNY Downstate, the Flatbush YMCA and NYC DOH** to host an in-person transplant seminar.

NKF Greater New York is committed to ongoing collaboration with CERCA to continue to develop and grow the Black Kidney Health Matters initiative.



Next steps:

- Patient Engagement Plan due **Friday, May 19th 2023** by noon to Adriana Joseph, ajoseph4@health.nyc.gov
- CERCA Meeting #10 will be **Friday, May 19th, 2023** from 1:00 to 2:30pm EST.